



We are working together for an inclusive Europe

EmpoweRARE

Empowerment of people with rare diseases

The disease may be rare but not the care!

PROJECT NEWSLETTER

Issue 5

MARCH 2021

Project information:

Project abbreviation: EmpowerARE

Project number: ACF-231

Call Topic: SEC-12-FCT-2017

Project start date: 01 October 2019

Duration: 20 months

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#STRONGERTOGETHER

International Rare Disease Day

International Rare Disease Day is held on the last day of February each year. The main goal of Rare Disease Day is to raise awareness among the general public and people making decisions about rare diseases and their impact on patients' lives.

How did the celebration of this international day start?

Rare Disease Day was first celebrated in 2008 on February 29, a day that comes once every four years. Since then, Rare Disease Day has been celebrated to raise awareness on the last day of February, a month with fewer days than others. The event was launched by EURORDIS-Rare Diseases Europe, a non-profit alliance consisting of 956 organizations of patients with rare diseases from over 73 countries. Members work together to improve the lives of people suffering from rare diseases.

The campaign initially started in Europe in 2008 and the United States joined in 2009. In 2020, more than 100 countries took part in the event. In 2021, thousands of events are held and over 1,200 stories are shared in 103 countries on six continents.

Rare Disease Day is an opportunity to raise awareness of rare conditions and stimulate improved access to care, treatment, information and support.

The 14th International Rare Disease Day was celebrated on **28 February 2021**, coordinated by EURORDIS. On this day and around it, hundreds of patient organizations from countries and regions around the world are working to raise awareness of rare diseases that affect nearly 300 million people worldwide.



RARE DISEASE DAY 2021
28 FEBRUARY



Rare Disease Day is held to spread awareness of rare diseases and the need to act now to recognize such diseases earlier. There is an urgent need to find solutions to challenges related to diagnosis, research, treatment costs, prevention, data collection and the general lack of awareness of rare diseases. According to reports, there are about 6000-7000 diagnoses of rare diseases worldwide. ***Most rare diseases do not have proper treatment and it can take up to seven years to diagnose the disease.***

With millions affected by rare diseases, it is very important for both the public and private ecosystems to come together, consider and find solutions, grants, innovations and funds.

Start-ups in the field of medical research are working to solve the problem. More efforts are needed, however, in research, government support, funding and policies to help address this crisis.

The number of people affected by rare diseases is equal to the population of the world's third largest country.



Delayed diagnosis, misdiagnosis or lack of diagnosis - this is the reality of people suffering from rare diseases

If you have a rare disease, the search for a diagnosis can often take years. It may seem that things are going nowhere, even for years.

Sometimes this is so because information about the condition is simply not available and not enough research has been done; in other cases, it is difficult to find someone sufficiently informed to notice the signs of a rare disease. After all, these diseases are so rare that many doctors have never encountered them in their careers. Either way, a person with a rare disease may eventually become an expert in their own medical mystery - and in some situations even solve the case or find a cure for themselves!

Many! Strong! Proud!

Connection between continents on Rare Disease Day!

The Rare Diseases Community and its supporters come together to share the message:

Rare diseases are many. People with rare diseases are strong. The person with a rare disease is proud!

(cited from <https://rarediseaseday.org>)

RARE DISEASES DAY

RARE DISEASE DAY 2021 IN BULGARIA

**The National Palace of Culture in Sofia lit up in blue, purple,
pink and green on the 28th of February 2021**

An event organized by the National Patient Organization in Bulgaria

On February 28, 2021, at 13:00 in front of the National Palace of Culture in Sofia, patients with rare diseases symbolically painted their hands in different colours, which stands for their difference and struggle for life.

From 18:30 to 23:00 the facade of the National Palace of Culture was illuminated in blue, purple, pink and green - the main colours of the movement of people with rare diseases.

"We believe that by lighting up the National Palace of Culture, a building of high public importance and cultural value for our country, we will draw people's attention to rare diseases in Bulgaria, thus becoming more recognizable and therefore people suffering from them - more visible in society ", commented Victor Paskalev, Deputy Chairman of the National Patient Organization.

"The world of people with rare diseases remains invisible to society. If we get to know them and hear their stories, and if we learn more about their disease that makes them different, I am sure we will realize how strong they are and realize that they exist. We will understand that they have a place among us on the labour market ", added Natalia Maeva, member of the Management Board of NGOs and president of the Bulgarian Society of Patients with Pulmonary Hypertension.

BILATERAL BULGARIAN-NORWEGIAN WEBINAR FOCUSED ON RARE DISEASES

Organized by the Bulgarian Huntington Association and FRAMBU, Norway

On February 27 and 28, Bulgarian Huntington Association and the Norwegian Resource Center for Rare Diseases FRAMBU (Frambu kompetansesenter for sjeldne diagnose) held a bilateral webinar on rare diseases, organized as part of the EmpoweRare project - Empowering People with Rare Diseases.



Двустранин онлайн семинар**Българска Хънтингтън Асоциация и Ресурсен Център за редки болести FRAMBU**

Iceland
Liechtenstein
Norway

Active
citizens fund

BULGARIAN
HUNTINGTON
ASSOCIATION

FRAMBU

EmpowerARE

EMPOWERARE

Проектът Овластяване на хора с редки болести се изпълнява от Българска Хънтингтън Асоциация с финансова подкрепа, предоставена от Исландия, Лихтенщайн и Норвегия по линия на Финансовия механизъм на ЕИП. Основната цел на проекта е овластяването на хора с редки болести в България.

Февруари | Февруари
27 | **28**

▶ 27 Февруари - Програма / February 27 - Program

▶ 28 Февруари - Програма / February 28 - Program

TOGETHER WE ARE STRONG!

The COVID-19 pandemic deprived us of the opportunity to visit Norway and get acquainted with the "live" experience and good practices of our partner from a donor country that has many years of experience in service models and empowering people with rare diseases. As a partial compensation for this loss, experts from the health resource center for people with rare diseases FRAMBU prepared a presentation of their expertise and good practices, which the participants of the bilateral webinar on the project got acquainted with. Here we present the second part of their extensive review - to serve as a reminder of the webinar participants and as an introduction to those who did not get the chance to participate.

As after the trainings and after your acquaintance with the FRAMBU presentations, your active involvement and feedback on what you find portable in our national context and how, in your opinion will be expected, the transfer of good Norwegian practices should be prioritized.

We wish to propose and contribute to the introduction of new specialized services for people with rare diseases, which are currently lacking in Bulgaria, but it is undoubtedly necessary to assess these on the basis of experience and consultation with specialists the portability, efficiency and effectiveness of existing services in Norway.

You who live with rare diseases are the experts in practice who can advise us. Do it!

THE EXECUTIVE TEAM OF THE PROJECT EXPRESSES ITS APPRECIATION TO ALL PARTICIPANTS WHO TOOK THE TIME TO PROVIDE FEEDBACK, WHICH IS ESSENTIAL FOR THE PLANNING OF FUTURE ACTIVITIES THAT ARE OF THE MOST USE TO YOU!

EXPERTISE AND GOOD PRACTICES AT FRAMBU

The Norwegian partner in the EmpowerRARE project is a large and functional resource health center with all the necessary mechanisms for access for people with disabilities. It was established as a health center focused on rare diseases in 1975. Since 1994, it has been a meeting place for people with rare diseases, their families and their helping professionals. According to his mandate within Norway, the FRAMBU center is responsible for supporting people with more than 450 rare diseases who are treated with a diverse interdisciplinary approach. His clients live their lives in their homes and services are provided to them in their homes and locally as far as possible.

The main principles of the center are: Family care, knowledge-based practice, health improvement, empowerment (health pedagogy) and consumer participation.

The Norwegian Ministry of Health and Care allocates funding and determines the diagnoses for which the FRAMBU is responsible. The focus and framework for the work and services provided by the center are determined by national law. An important detail is that the services of the center are a complement to the available local service, not a substitute, and the services of the center are organized with a multidisciplinary approach based on practical experience and evidence with a family approach to care. The center requires and facilitates the participation and cooperation between local service providers (medical, educational, work, housing, social services, etc.).

➤ **The method of service use** at the center is as follows:

Patients and their families must apply for counselling services (by filling in an application form).

General criteria for access to services include:

The topics and issues to be covered should be related to a specific diagnosis

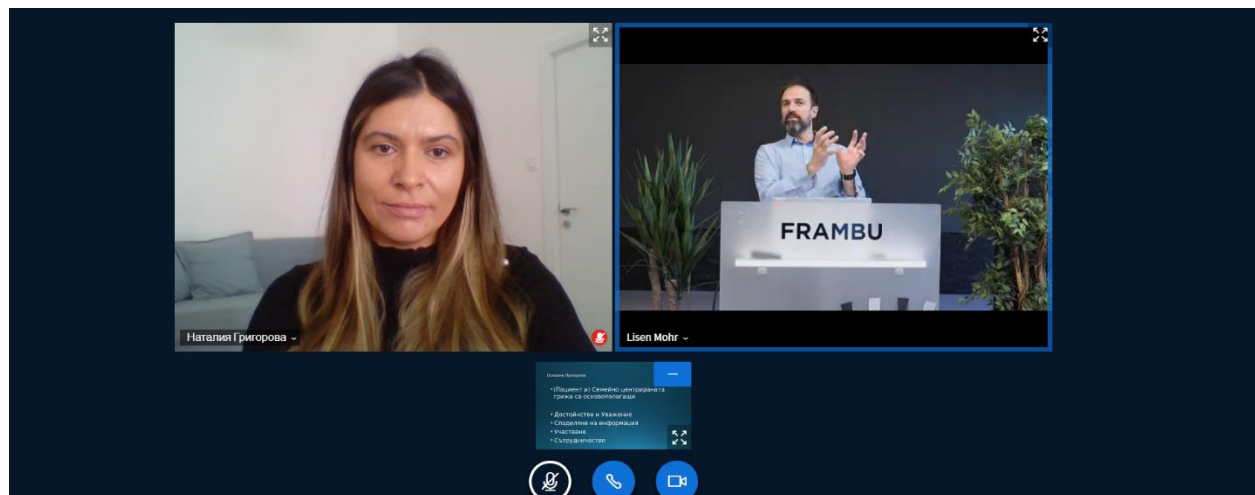
- ✓ Local professionals are not able to offer the same service
- ✓ The same service has not been previously available to the family and the patient

- ✓ To cover newly diagnosed patients and rapidly progressing diagnoses, as well as complex cases
- ✓ Offer on-site services, not digital services
- ✓ The purpose of the service should be to build a knowledge base of FRAMBU and / or to be the main focus of the training of employees providing local services

The criteria for offering counselling to groups of professionals are:

- ✓ Local and regional service providers can apply for more advisory services (by filling in an application form)
- ✓ Increasing the knowledge base at the local level related to the diagnoses for which we provide services
- ✓ Organized regional / local consultation, which helps to facilitate the local network of professionals

Usually local / regional professionals and service providers apply, but also patient organizations / associations. Families and patients are usually not involved.



➤ **Summer Training Camps at FRAMBU**

The tradition of holding summer training camps for families with serious health problems has existed in the community that serves the FRAMBU health center since 1955. Usually 3 separate summer camps are held annually with a duration of 11 days each, with age limits of participants from 12-30 years. 50 participants and 45 workers in its implementation are included in each camp.

The main goal of the summer training camp is:

- ✓ Offering a holiday experience in a safe and inclusive environment
- ✓ To be an arena of learning and experience opportunities that can help participants in their daily lives at home

- ✓ Enabling participants to meet others in similar situations like them so that they can share experiences, connect and build social networks

This is an extremely popular activity of the center with a large number of applicants and preparation of a waiting list for participation. In the summer of 2020, this 65-year activity was abruptly cancelled by the outbreak of the COVID-19 pandemic.

Organization of the summer camp

- Using the facilities of the Frambu Resource Center, all participants and workers stay in the camp for 11 days with accommodation and food provided.
- Approximately 5-10% of Frambu's total budget is used for summer camps, so the camps cost participants nothing but a small amount of pocket money.
- The center employs a number of unskilled workers each year, but has a majority of experienced workers with many years of experience in running summer camps.



Frambu experts, although faced with the ban on holding mass events, decided not to give up completely in 2020 and found a solution in the implementation of the summer camp in a digital version.

The concept of the digital alternative includes:

- Videos published on frambuleir.no from 13 to 19 July, a total of over 80
- Open platform, without registration
- New content delivered twice a day - entertainment, concerts, activity guides, live show, test and more
- Activity of participants such as viewers can send photos and videos that are displayed on the website and in videos.

The chosen **format and platform**

- Providing videos twice a day instead of live streaming - so no one feels abandoned in result of their personal schedule
- Striving to be as easily accessible as possible
- Interaction between viewers and workers by encouraging viewers to share photos from their summer and then appear on the website and in some videos
- Videos uploaded separately to the web page so viewers can easily watch what they want

Various types of content



Popularization of the digital camp

- Sending letters by regular mail to all applicants for summer camp during the year
- Active use of Facebook, both before and during the digital summer camp
- Publishing information about the summer camp on our website
- Sending emails to other organizations that everyone is invited to participate

Feedback from participants

- Although it could not compete with a normal summer camp, it was appreciated by spectators
- Viewers who were interviewed later wanted a digital camp next year, along with regular camps
- Not just a one-time event, but with the intention to develop further

All presentations and recordings from the two-day webinar can be found on the project website www.empowerare.eu



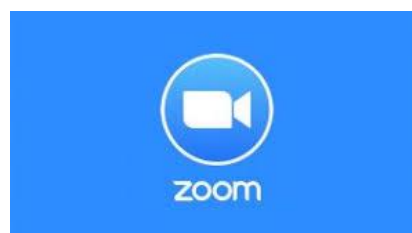
Ongoing trainings on the project "Empowerment of people with rare diseases" (EmpowerRARE)

With the approval EmpowerRARE project's extension until the end of May 2021, Bulgarian Huntington Association and Norwegian FRAMBU center were given the opportunity to conduct more trainings for people living with rare diseases and their relatives and carers, to increase awareness, understanding and support of their human rights and the new legal provisions. These trainings, for the dates of which you will be informed in a timely manner, will be in accordance with the topics proposed by the participants from previous trainings, their stated wishes and the emerging new needs.

The chosen model for forming training teams with the participation of experts from practice, people with rare diseases will continue to be used, as will the practice of planning the trainings in accordance with the expressed wishes and recommendations in the feedback of the target group which proved its effectiveness.

For current dates and formats of the trainings, please follow the project website and the social media page.

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WE WILL CONTINUE TO BE TOGETHER!
OUR NEW PROJECT “HUNTINGTON’S DISEASE WEEK”

We are happy to announce that after the conclusion of the EmpowerRARE project, we will continue to be together with our next small project - HD WEEK (Huntington’s Week). We are happy to be one of the organizations whose project to overcome the consequences of the COVID-19 pandemic was approved for funding.

Our main goal with this project in response to the increased needs of people with rare diseases is to assemble the group in person, in order to reduce the negative effects brought about by the COVID-19 related restrictive measures on people affected by Huntington’s Disease. Huntington’s Week - a 5-day training camp - aims to bring families affected by the disease out of social isolation by bringing them together in joint activities, discussions and collaboration with treatment professionals, to strengthen the support network empowering them to help each other, to encourage their close cooperation and for professionals to engage with them, attributing to the development of professional expertise. Complementary activities related to the rehabilitation of patients will also be held.

The activities are planned for implementation in the period June - September 2021, in accordance with the situation in the country and the negotiating the best framework for its implementation, keeping in mind the modest budget of the project.

We believe that the participants of the first similar Week for people affected by Huntington’s Disease, conducted with the participation of foreign experts from the Netherlands, Germany and Malta in June 2019 with funding from the Griffin Foundation, were pleased with the event and felt the unification of our community affected by Huntington’s Disease and the professionals supporting them.



By conducting a new "Huntington’s Week” we aim to rebuild and strengthen contact in the community affected by the disease, between each other as with the professionals, to

achieve a better understanding of the disease and its progression amongst those affected, through familiarization with current research in the field.

The team of the Bulgarian Huntington Association is already preparing for the implementation of the new project with internal training to increase its capacity and planning and preparation of the necessary training materials for the upcoming event.

We will keep you informed, but you can also follow the news on our website and on our social media. We will rely on your feedback from the last two trainings under the EmpoweRARE project, so that we can include the most desired topics in the training camp program.

Let's not forget - **We are going to hold more trainings - group and individual and a round table, as well a final press conference on the EmpoweRARE project! Invitations and information for future events can be found on the project website www.empowerare.eu**

**THE EMPOWERARE TEAM WOULD ONCE MORE LIKE TO VOICE
THEIR APPRECIATION FOR THE VALUABLE INFORMATION
THROUGH YOUR FEEDBACK, WHICH WE LOOK FORWARD TO
ALSO RECEIVE IN THE FUTURE!**

WE ARE STRONGER TOGETHER!



Keep yourself informed!

For more information, please visit the project website: www.empowerare.eu

Facebook: <https://www.facebook.com/empowerare/>

Instagram : <https://www.instagram.com/huntington.bg/>

You tube : https://www.youtube.com/channel/UCcZDultF90H_4TZ5hyfigdQ



This document was created with the financial support of the Active Citizens Fund in Bulgaria under the Financial Mechanism of the European Economic Area. The sole responsibility for the content of the document lies with the Bulgarian Huntington Association and under no circumstances can it be assumed that this document reflects the official opinion of the Financial Mechanism of the European Economic Area and the Operator of the Active Citizens Fund in Bulgaria..
www.activecitizensfund.bg